DOCUMENT RESUME

ED 323 685 EC 232 111

AUTHOR Walker, Pam
TITLE Family Supports for Children with Severe Disabilities and Chronic Illnesses in Maryland.
INSTITUTION Syracuse Univ., NY. Center on Human Policy.
SPONS AGENCY National Inst. on Disability and Rehabilitation Research (ED/OSERS), Washington, DC.
PUB DATE 88
CONTRACT 300-85-0076; G0085C03503
NOTE 28p.
AVAILABLE FROM Syracuse University, Center on Human Policy, 200 Huntington Hall, 2nd Floor, Syracuse, NY 13244-2340 ($2.10).
PUB TYPE Reports - Descriptive (141)

EDRS PRICE MF01/PC02 Plus Postage.
DESCRIPTORS *Chronic Illness; Delivery Systems; *Family Programs; Financial Support; Home Programs; *Human Services; Respite Care; *Severe Disabilities; *Social Support Groups; Teamwork
IDENTIFIERS *Maryland

ABSTRACT

This report focuses on positive practices in providing support services to families of children with severe disabilities and chronic illnesses, based on visits to three sites in Maryland: the Family Support Program at the Kennedy Institute in Baltimore, the Coordinating Center for Home and Community Care, and Sick Kids Need Involved People (SKIP). The three programs are described, followed by discussion of the key family support issues and practices that were identified. Key issues include: a family-centered approach to family support, individualized and flexible supports, financial supports, respite, in-home care for children with medical needs, and social/personal support for families. A team approach to family support and effective service coordination are also exhibited by these programs. Resources for funding family support services are briefly described. Includes four references. (JDD)

****
* Reproductions supplied by EDRS are the best that can be made *
* from the original document. *
****

U.S. DEPARTMENT OF EDUCATION
Office of Educational Research and Improvement
EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)

☐ This document has been reproduced as received from the person or organization originating it.

☐ Minor changes have been made to improve reproduction quality.

• Points of view or opinions stated in this document do not necessarily represent official OERI position or policy.

FAMILY SUPPORTS FOR CHILDREN WITH SEVERE DISABILITIES AND CHRONIC ILLNESSES IN MARYLAND

"PERMISSION TO REPRODUCE THIS MATERIAL HAS BEEN GRANTED BY

S. Taylor

TO THE EDUCATIONAL RESOURCES INFORMATION CENTER (ERIC)."

FAMILY SUPPORTS FOR CHILDREN WITH SEVERE DISABILITIES AND CHRONIC ILLNESSES IN MARYLAND

1988

Pam Walker
Center on Human Policy
Syracuse University
200 Huntington Hall, 2nd Floor
Syracuse, NY 13244-2340

Acknowledgment is given to the contribution of Julie Racino, Steve Taylor and Bonnie Shoultz for their review and commentary on previous drafts. Preparation of this site visit report was supported in part by the U. S. Department of Education, Office of Special Education and Rehabilitative Services, National Institute on Disability and Rehabilitation Research under contract nos. 300-85-0076 and G0085C3503 awarded to the Center on Human Policy, Division of Special Education and Rehabilitation, School of Education, Syracuse University.

FAMILY SUPPORTS FOR CHILDREN WITH SEVERE DISABILITIES AND CHRONIC ILLNESSES IN MARYLAND

Pam Walker

Center on Human Policy

1988

In the past few years, increased emphasis has been placed on the importance of children living at home with families in the community, rather than in institutional or group settings (Center on Human Policy, 1986). In order for this to happen, particularly for children with severe impairments and chronic medical needs, it is necessary to offer families the supports they need to keep their children at home. Innovative programs in states such as Wisconsin and Michigan are providing families with a broad range of types and levels of family support (Taylor, 1985; Taylor, 1987). In Maryland, also, there are examples of intensive and individualized supports available for some families of children with severe and multiple disabilities (see, for example, Bersani, 1987).

This report focuses on some of the positive practices in Maryland in family supports, especially for families with children who have severe disabilities and chronic illnesses. It is based on visits to three sites selected by a subcommittee of

the Maryland Developmental Disabilities Planning Council: the Family Support Program at The Kennedy Institute in Baltimore, the Coordinating Center for Home and Community Care (CCHCC), and SKIP (Sick Kids Need Involved People). These visits, conducted as part of the work of the Community Integration Project in Maryland in June 1987, included interviews with program staff and visits to families who receive assistance from these programs. The purpose of the site visit was not to evaluate these services, but to identify and document good practices in supporting children with extensive health needs in Maryland. A brief description of each of the sites is presented below, followed by discussion of the key family support issues and practices that were identified.

Family Support Services, The Kennedy Institute. The mission of the Department for Family Support Services is "to provide support services designed to enable families and family care providers to meet the needs of a developmentally disabled child living in the home." The Department for Family Support Services consists of three programs: the Child and Family Support Program; the Family Centered Planning Program; and the Family Support Services Program. The Child and Family Support Program provides in-home training, counseling, and service coordination for about 125 families of children from birth to 7 residing in Baltimore City or Baltimore County. Approximately 25 of these children are considered to be chronically ill or medically fragile. The Family Centered Planning Program serves

approximately 50 families with children birth to 21 years of age, offering service coordination and pulling together a team of professionals and community members as a network of support for the family. Finally, the Family Support Services Program assists children from birth to 21 residing in Baltimore City, Baltimore County, and Anne Arundel County who are considered at-risk for out-of-home placement. Supports to families may include convening a team of support for the family, assisting the family with access to services or service coordination, and/or assistance with the purchase of needed services. As of June 1987, this program served approximately 75 families.

Coordinating Center for Home and Community Care (CCHCC). The Coordinating Center for Home and Community Care (CCHCC) is a nonprofit organization funded by a federal SPRANS (Special Projects of Regional and National Significance) grant. Originally established in 1983, its mission is "to create alternatives to lengthy and repeated hospitalization for children who require medically complex care." This is achieved through the cooperative effort of a "consortium" of service providers, agencies, and organizations that CCHCC is composed of, including medical facilities, community organizations, funding organizations, academic institutions, and others. CCHCC provides service coordination and case management for children who receive supports through Maryland's Model 50 Medicaid waiver. To be eligible for CCHCC services, an individual must be (1) eighteen years of age or younger; and (2) a resident of Maryland. The agency originally restricted its services to "respiratory

disabled" children. However, it has now expanded the criteria for enrollment to include other children requiring medically complex care, who are not necessarily "technology-assisted." To qualify for CCHCC services, a child must have been hospitalized for 30 days or more, or be at risk of long-term or repeated hospitalization. In addition, the child must (1) be medically stable; (2) need special support in the home to avoid long-term or repeated hospitalization; or (3) need specialized equipment or care in order to remain at home with minimum risk. As of June 1987, 68 children were currently being supported by CCHCC statewide; a total of 208 children have been served since the program's inception.

SKIP (Sick Kids Need Involved People). SKIP is a support and advocacy group for parents of children who are chronically ill. It is a national organization, composed of local chapters, whose purpose is to offer education, resources, and support to families. The educational component involves development of written materials for parents and professionals. Currently SKIP has a grant from the U. S. Department of Education to produce the fourth edition of a handbook for parents. In acting as a resource, SKIP identifies existing resources and builds on them. SKIP members work to "help the system help families." This involves educating professionals through participation of SKIP members at meetings, conferences, special committees, task forces, and so forth. Finally, as a source of support, SKIP's aim is to "help families to help themselves" by assisting them to identify and obtain access to needed resources.

Family-Centered Approach to Family Support

Some agencies in Maryland are taking a "family-centered" approach to supporting families of children with disabilities. These agencies try to support families on the basis of the needs of the entire family, rather than just the needs of the child with disabilities. One staff member explained that a family-centered approach might mean "looking at needs according to what the family says, versus just the priorities of the physician." From the start, the family is involved in all aspects of planning and decision-making. Another staff member commented about this approach: "We go by families' priorities...it's really family focused...I think that's one of the strengths of this program." As an organization, SKIP also stresses the importance of a family-centered perspective. The founder, Karen Shannon, emphasizes: "The family has to be the nucleus, instead of the system being the nucleus..."

Individualized and Flexible Supports

An individualized approach tailors supports to the needs of particular families. It begins by asking families what they need to keep their child at home. The types and levels of support provided vary depending upon the family's needs. Some of these supports and their application to children with severe disabilities and chronic medical needs are discussed below.

Financial Supports

Financial support is often needed by families to assist with expenses either directly related to their child, such as for medical costs, adaptive equipment, and other items not covered by Medicaid, or for more general household expenses.

One of the families receiving support from the Family Support Services Program (FSSP) at The Kennedy Institute are the Millers*--Jeff and Susan, and their two children Jan and Doug. The supports they receive illustrate some of the needs of one family and the ways they are supported.

> The Millers live in a middle-income neighborhood of row houses in the city of Baltimore. Upon entering their house, one is struck by the hominess of it--the worn but comfortable and attractive furnishings, the family photographs and momentos throughout the house, and the invitation to sit down to a freshly brewed cup of coffee. One is also immediately struck by the hospital-like bed in one corner of what would have been the dining or living room area. Next to it on the floor is a large mattress. This special bed is for Doug, the mattress for his father, who sleeps downstairs at night to be with him. As we entered the house, Cindy, the Program Coordinator of FSSP commented, "You see, this is very much a Doug house."

*All names throughout the report, except for agency personnel, are pseudonyms.

Doug, who is 10 years old, is labeled severely mentally retarded and has cerebral palsy. He does not walk, is blind, and often has seizures. He needs assistance with all of his self-care routines, and is fed through a g-tube. Since he was an infant, Doug has been hospitalized on the average of 8-9 times a year with repeated bouts of pneumonia, bronchitis, and various other infections.

It costs about $500-600 per month to maintain Doug at home (excluding the costs of his recently begun nursing care). Jeff earns $20,000 per year--not enough to cover all of Doug's expenses in addition to routine household bills. The Family Support Services Program has provided a monthly stipend of $150 per month, as well as additional help as needed for respite. The FSSP also assisted the parents in paying for some counseling for their daughter.

Although expenses such as utility bills and personal counseling are not directly related to Doug, assistance with them seems to have a significant impact upon this family's ability to maintain their child at home.

Above all, it is important to remember that the financial assistance needed will vary from one family to another: some families may not need any extra assistance; some may need one-time assistance with a major purchase or expense; and others may need regular, on-going assistance.

Respite

Making adequate respite available to families of children with severe disabilities and chronic illness presents a challenge. Parents of children with these types of needs are often hesitant to leave their child in the care of a stranger or someone they do not feel is adequately trained in his or her care. Within Maryland, there is some effort to provide respite for families with children who are severely disabled. For example, some families are given funds to hire their own respite provider, someone they know and are comfortable leaving their child with. Through the Family Support Program at The Kennedy Institute, Susan Miller is able to have a family friend, Betty, come stay with Doug from time to time. Betty is the only person outside of the family and Doug's nurse that Susan will leave him with; when Betty is not available, Susan will not go out. The Coordinating Center for Home and Community Care encourages families to have relatives and close friends be trained in the care of their child so these people can provide respite for either planned occasions or emergencies.

Overall, there are some positive steps being taken in Maryland to provide respite to families of chronically ill and severely disabled children. It is particularly notable that some families are able to select their own respite providers, and can pay relatives, neighbors, or friends for this type of support. However, there is still a lack of respite for families with children who are severely disabled and chronically ill and many of these families remain very isolated. There is need both for

more resources directed to respite as well as an increase in amount and flexibility of funding, allowing families to hire people they know and/or those who they feel are well-trained enough to provide respite for their children with complex needs.

In-Home Care for Children with Medical Needs

To bring children who are chronically ill home to live, it is often necessary to arrange for in-home medical care. As the agency in Maryland providing service coordination for children supported by the Model 50 Medicaid waiver, CCHCC has been involved in facilitating the discharge of many children from hospitals. Prior to discharge, CCHCC convenes a meeting to develop a long-term "plan of care." Participants in this meeting include the family, the physician, the home care providers chosen by the family, a representative of the payer (whoever is paying for the home care and other medical supports, such as Medicaid or a private insurance agency), and other CCHCC staff including the financial coordinator, educational coordinator, and clinical coordinator. Before a child returns home to live, hospital staff train the parents in all aspects of care for their child. The parents then hire and train their own nurses, with assistance from CCHCC. A clinical coordinator from CCHCC visits each family within 48 hours of discharge, then once a week for the first month, once every other week for the next month, and once a month thereafter.

Michelle, who is 6 1/2 years old, lives at home with her parents and younger sister. When she was a year old, she had a brain stem infection leading to a condition known as "central hypoventilation syndrome," in which her breathing is impaired and she does not get sufficient oxygen to her brain. As a result, Michelle has had a tracheostomy, receives oxygen throughout the day, and has been on a ventilator at night since 1984. Michelle has to be tube-fed because she has no swallow or gag reflex. At night she is on an apnea monitor since she frequently stops breathing. She needs to be suctioned about every 3 hours. Through the Medicaid waiver, Michelle receives nearly 100 hours of in-home nursing per week: Monday-Friday, 7:00am-3:00pm; Sunday night-Thursday night, 11:00pm-7:00am; and Friday and Saturday night, 11:00pm-8:00am. When there are no nurses present, Michelle's parents provide the medical care she needs. Priscilla, an R.N., is the clinical coordinator from CCHCC for Michelle's family. She visits them "about once a month," and talks to them on the phone "about four times a week."

While home care for many children in Maryland has been financed by the Model 50 waiver, state developmental disabilities dollars and private insurance have also paid for some of these types of supports. There are problems with each. First, state funds for intensive in-home supports have been limited, and have

not been used for such intensive home care on a routine or on-going basis. Second, private insurance companies are hesitant to cover children with chronic illnesses. Debbie, the mother of Joe, a child who is technology assisted, related some of her family's experiences with private insurance.

Joe, who is 6 years old, was born with cerebral palsy and "respiratory distress syndrome." Related to this, he has a weakening of the trachea, causing it to collapse, and difficulties in breathing. Debbie commented, "He has respiratory arrests all the time"--up to 25 times a day. Both parents work--Debbie in the evenings and her husband, Ed, during the day. They have 24 hours of nursing a day during the week, and nursing just at nights on the weekends.

The supports for Joe used to be covered by their private insurance, but this was terminated. In trying to get the coverage extended, Debbie talked about the difficulty of gaining access to the person at the insurance company whom they needed to talk to. She commented, "We weren't getting anywhere through the proper channels." She described how "we finally went running up to catch him in a parking lot...That's not the way we used to think of doing things...but that's what you have to do to get anything." Finally, she explained, "I wrote to President Reagan about our situation, and he intervened and got it (the coverage) extended for 90 more days. After this 90 days, though,

he was again terminated." Now, her husband is employed with a new company, and Joe's medical supports are covered by a new insurance agency.

Having in-home nursing up to 24 hours a day requires adjustment and adaptation of the entire household. According to Karen Shannon, of SKIP, it is something that families of children who are chronically ill and technology-assisted have to accept if they are to bring their children home from the hospital. Regarding characteristics she looks for in a prospective nurse, Michelle's mother commented, "I think it's most important that they are dependable and willing to learn." Joe's mother, Debbie, said she has fired nurses both because she did not feel they were competent and because of an "I'm the nurse" attitude. Rather than having a nurse be in control and make the decisions, Debbie prefers working together with the nurse. She commented, "you need to work as a team with the nurses." Stressing the importance of the family's relationship with the nurse, Karen Shannon pointed out that "it is important to be selective, personality-wise, in terms of nurses...you have to get nurses that you get along with and feel comfortable with." After a few years, nurses may "become like part of the family." Yet, nurses also come and go, and families must periodically find new nurses due to this turnover. At times, a family may be short one shift and the parents handle the situation as best they can, taking turns staying up nights with their child. New nurses are not always easy to find since there is a statewide shortage of

nurses. Having nurses in one's home can also be invasive of privacy, and families talk about a need for time out without the nurses. One mother emphasized, "Families need to be allowed to be families."

For nurses, too, in-home nursing requires some adjustment. Priscilla, a Registered Nurse, is one of the Clinical Care Coordinators for CCHCC. As such, she visits families once every few weeks to monitor the supports they are receiving. She feels that in-home nursing is quite different from most traditional nursing practice. She explained that in this home care role, "we do a lot of non-nursing things, such as a social work role, or deal with educational issues...I think that's the most difficult thing for nurses to adjust to in this kind of work."

In summary, the in-home medical care available in Maryland has provided the opportunity for many children to live at home who otherwise would have spent much if not all of their lives in hospitals or nursing homes. One mother commented about her 6 year old child who is ventilator-assisted, "He thinks of himself as a normal child...The biggest reward of home care is they're kids, just kids, never looked at as different kids." As with other types of family supports, this type of care must also be both individualized and flexible: some families may need a few hours of nursing per week while others need up to 24 hours a day; and the needs of any one family for full-time versus part-time nursing may remain constant or vary over time. And, there is need for additional resources directed to providing in-home medical and other supports. This should include increases in the

supports provided to families--not only for those with children labeled as "chronically ill" or "medically fragile," but for all children with disabilities, based upon needs of the child and family. In addition, efforts should be made to create and train an adequate pool of in-home care providers.

Social/Personal Support

In addition to supports such as nursing care, financial assistance, and respite, families of children with disabilities also need social or personal supports. Sometimes they get this through organized support meetings. For Susan Miller, the parent support group at The Kennedy Institute has been helpful, and she feels that the sibling support group was good for her daughter, Jan.

At other times, they receive support from individual people, both professional and nonprofessional. Susan also commented how Cindy, the Program Coordinator of the FSSP, has been an invaluable source of moral support. "I don't know what I would have done without her...I couldn't have done it without her...She's been a life-saver." Linda and Debbie, both mothers of children labeled "medically fragile," mentioned particular doctors who had always had "time to listen," or to let them "talk things out" when they needed to. Debbie also related how some of her nurses had continued to come on a volunteer basis when her son's insurance was terminated.

Linda and Debbie both have also received significant personal support though SKIP. While it may be difficult for parents of medically fragile and technology-assisted children to

meet as a group, SKIP promotes the development of networks of "telephone friends" for mutual support. Therefore, through SKIP they can receive support themselves as well as offer support to others at the same time.

Summary: Individualized and Flexible Supports

There are a wide range of supports needed to maintain children with severe disabilities and chronic illnesses at home. These include supports provided directly to the child with disabilities, as well as assistance to the family as a whole. Further, the types and intensity of support needed will differ from one family to another, and are likely to change over time. Financial or medical support alone are generally not sufficient; families also need social and emotional supports. If all children with disabilities, including those with the most severe impairments, are to remain with or return to families, then it is essential to ask families what they need for support, and to offer individualized and flexible supports. For example, when asked about the types of support families receive, staff of the Family Support Program at The Kennedy Institute respond, "That depends on the family." And, regarding the level of supports provided, they respond, "Whatever the family needs."

A Team Approach to Family Support

Agencies providing innovative family supports in Maryland are doing so in a way that involves a team effort. The family is an integral and central part of that team. Additional team members are selected based upon the family's and child's needs

and circumstances. They may include physicians, nurses, physical therapists, occupational therapists, speech therapists, nutritionist, educators, case managers and/or social workers, fundors, and family friends, relatives, and neighbors--"whomever the family identifies as being important."

Lynne Brown, who is a year old, has trisomy 13. As a result, she has multiple disabilities, including blindness, grand mal seizures, and kidney damage. She is beginning to make some vocalizations and roll over independently. Lynne lives in a small apartment with her mother, Cathy, and her grandmother, Ellen. They receive supports from the Child and Family Support Program at The Kennedy Institute. They first contacted CFSP through a hotline. At that time, they had been receiving pressure from their pediatrician to place Lynne into an institution.

Initially, Lynne went for an evaluation at The Kennedy Institute. After this evaluation, the family was assigned a primary support person from the CFSP, Mary, a Pediatric Nurse Practitioner. At this point, Mary met with the family along with other relevant team members from CFSP to set priorities. They will meet every six months after this to review progress and priorities. At the outset, Mary also contacted the family physician to introduce herself and to explain CFSP involvement. Mary visits the family about once

every two weeks, possibly more often at first. Based upon the evaluation, an occupational therapist and physical therapist will visit the family once a month, at least for awhile, to train the mother and grandmother in handling, positioning, and other assistance for Lynne.

Although the pediatrician was recommending out-of-home placement for Lynne, the family has decided to keep her at home with the support from CFSP. Ellen talked about what it was like before: "With the pediatrician, everything was negative...she told us Lynne would never walk, talk, roll over, or eat regular food, but she is starting to do all of t' e." However, despite this pediatrician's ne ivity, the family has retained her as their pedia: cian, since they feel she is a competent person. Also, Mary explained that she is a young pediatrician, who is really "coming along" with this family, and learning a lot from seeing them keep Lynne at home.

CCHCC also works with a team concept to help bring children who are chronically ill home. Upon referral of a family, the family services coordinator conducts a family needs assessment (including environmental needs, architectural barriers, adaptations, special equipment, etc.). Each family is then assigned a clinical care coordinator. Also, based upon the

family's and child's needs, other agency staff members may be called in, including the financial coordinator or educational coordinator.

The strength of the team approaches described above is that they help provide a broad base of support and assistance to the family. It is important that the family of the child with disabilities be a central part of this team. Another key to making this type of approach effective is communication between all participants on the team. Finally, it is important that the primary function of the team be to further connect the child and family to existing community services and resources.

Case Management/Service Coordination

An essential element of family support is case management, or service coordination, for families--connecting families to various medical, respite, counseling, financial, educational, and other support services. For example, the Planning Coordinator in the Family Centered Family Planning program at The Kennedy Institute works with families to assess current services and supports, determine additional service needs, advocate for these when necessary, and plan for the future. "The goal is to have parents take over the role of coordination of their own services, and advocacy for their child." The Planning Coordinator typically visits families every two weeks, or at least once a month. However, program staff emphasize that "the frequency of visits varies with each family, depending on their needs."

The Coordinating Center for Home and Community Care (CCHCC) provides care management and service coordination for families having children considered to be chronically ill. Many of these families have in-home nursing, and therefore have to deal with the responsibilities of obtaining and coordinating nursing care in their homes. Similar to the Family Centered Planning Program, CCHCC staff members see their role as going beyond that of typical case management, to include support of and advocacy for the family. One of the primary objectives is to have families eventually become their own case managers, and advocate for the rights of their child.

Priscilla, a R.N., has been a clinical coordinator for CCHCC since the program began in 1984. She works with a total of about 25 families, 20 of whom currently have their child at home. One of these families is that of Michelle. Priscilla visits the family about once a month, but talks to them on the phone "about four times a week." When they have a turnover in nurses, Priscilla helps them find new nurses.

Case management or service coordination is a crucial element of family support. At the same time, families report that it "can be very invasive." Without careful precautions, "case management" can readily become "family management," or taking over control for families. In light of this, it is positive that the agencies in Maryland are conceptualizing their role as one of "service coordination" rather than traditional "case management." The supports provided to families often go beyond

just "service coordination" to include social support for families. Also, as described in the following section, a strength of these agencies is their emphasis on empowerment of families.

Advocacy and the Empowerment of Families

The family support programs in Maryland have as one of their objectives the empowerment of families as a key to advocacy for the child with disabilities. The idea is to work with families to help them develop skill and competency as advocates. A staff member at one agency commented, "We don't do for families, we work with them." An advantage for programs such as the Family Support Programs at The Kennedy Institute and CCHCC is that they do not provide direct services. Therefore, agency personnel feel they are in a better position to advocate for services for families.

Toward this same end, one of the objectives of SKIP is to "help families to help themselves" by assisting them to identify and obtain access to needed resources and supports. The founder of SKIP, Karen Shannon, emphasized that the approach is a "hands-off" one--making recommendations and suggestions, but not telling people what to do. A parent of a child who is technology-assisted stressed the need for service coordination, especially at first, but commented that "case management can be very invasive." She emphasized that families need to be in control, to make the decisions, and acquire the skills "for handling

things and figuring out how to handle them." Another parent commented, "It's amazing how much stress is reduced when you have control."

Funding Family Supports

Family supports for children with severe disabilities and chronic illnesses in Maryland are funded in a variety of ways, which are briefly described below.

Medicaid Model 50 waiver. This Medicaid waiver provides funds for in-home supports to 50 children who have complex medical needs. At first, the program served only those children who were "ventilator-assisted," but has since expanded the definition to include a broader range of children who are either "technology-assisted" or chronically ill.

Medicaid Technology-Assisted Waiver. This Medicaid waiver provides funds for children with complex medical needs who are technology assisted. The funding covers things such as specialized medical equipment, in-home nursing, case management, and in-home visits by specialty physicians.

SPRANS grant. Through the Division of Maternal and Child Health, Maryland has a SPRANS grant (Special Projects of Regional and National Significance) which funds agencies such as CCHCC as a care management and service coordination agency. This agency provides care management/service coordination to children who have complex medical needs..

Developmental Disabilities Administration (DDA). The state Developmental Disabilities Administration provides funds for family support services, which include supports to families

having children with severe disabilities and chronic illnesses. There is significant flexibility in the types of supports that can be provided with these funds.

Developmental Disabilities Council. The Developmental Disabilities Council has used some of its funds to initiate or expand family support services, including supports to children with severe disabilities and medical needs.

In addition, the family support service agencies described in this report also use other available sources of support. For example, through a grant from the Hearst Foundation, The Kennedy Institute is undertaking a one-year pilot project, the Infant and Family Support Program. This program will provide supports to families with high-risk and medically fragile infants and will help identify and document the need for increased funding for this type of program in the state. Funds are also sought from sources such as the United Cerebral Palsy or the Society for Underprivileged and Handicapped Children. A one-time grant from one of these agencies might be used to help a family purchase a needed appliance or piece of adaptive equipment. Also families are assisted to obtain access to other sources of financial support that they may be eligible for, such as WIC, AFDC, private insurance, and so forth.

There are limitations attached to some of these funding sources. For example, Medicaid will only cover medical supports; yet, families usually have many additional needs. While Doug Miller receives about 60 hours of nursing a week through the Medicaid waiver, at the same time, his family receives additional

financial assistance and other supports through The Kennedy Institute. Thus, it is noteworthy that some agencies in Maryland are making an effort to access any available funds and/or pool various sources of funding. It is evident, based upon the families' experiences, that a few or even multiple sources of assistance may often be necessary to meet the needs of families and their children with chronic illnesses and other disabilities.

Adequate individualized supports are available in Maryland for families of some children with severe disabilities and chronic illnesses. However, funding must be made available, from a variety of sources, to enable all children with disabilities to live at home, receiving whatever supports are necessary.

Conclusion

This report highlights the positive practices of three agencies/organizations in Maryland with respect to supports for families of children with severe disabilities and chronic illnesses. Some of the key factors in providing such supports are that: (1) the focus of support is "family-centered"; (2) the supports are both individually tailored to the needs of children and families; (3) the type and level of supports provided are based not only on financial and/or medical needs, but on social/personal needs as well; (4) a team approach to support, with the family at the center of that team, provides a broad base of knowledge and input; (5) case management is thought of more in terms of "service coordination" than of "management;" (6) the focus of support is to empower families through assisting them to

advocate for the rights and services needed by their child; and (7) it is often necessary to use creativity in utilizing or pooling funding sources in order to provide needed supports for a family.

In Maryland, there are some particularly good examples of the following: (1) in-home medical supports and service coordination for children labeled technology assisted or chronically ill through CCHCC; (2) individualized and flexible family supports for a limited number of children with severe disabilities, some of whom are technology assisted or chronically ill, through the Family Support Services Program at The Kennedy Institute; and (3) organized parent support and advocacy for parents of children labeled technology assisted or chronically ill through SKIP. What is needed is that all three of these types of supports be available to <u>all</u> children with disabilities and their families.

References

Bersani, H. (1987). Report on Calvert County ARC, Family Support Services. Syracuse, NY: Center on Human Policy.

Center on Human Policy. (1986). A Statement in Support of Families and Their Children. Syracuse, NY: Center on Human Policy.

Taylor, S. (1985). Report on Macomb-Oakland Regional Center, Michigan. Syracuse, NY: Center on Human Policy.

Taylor, S. (1987). Community Living in Three Wisconsin Counties. Syracuse, NY: Center on Human Policy.